

# LEARNING FROM COLLEAGUES:

## *Family/Professional Partnerships*

## *Moving Forward Together*

A Product of the Peer Technical Assistance Network:

Center for the Study of Social Policy with  
Council of Chief State School Officers  
Federation of Families for Children's Mental Health  
National Resource Network for Child and Family Mental Health Services  
National Technical Assistance Center for Children's Mental Health

September 1998



# **Family-Professional Relationships: Moving Forward Together**



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**A Product of the**

**National Peer Technical Assistance Network's  
Partnership for Children's Mental Health**

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## PREFACE

*Family-Professional Relationships: Moving Forward Together* presents research and commentary on the issues involved in utilizing a family/professional partnership systems approach in situations involving children who have developed or are at risk of developing serious emotional, behavioral, or mental health disturbances and their families.

The document is the product of the National Peer Technical Assistance Network. The Peer Network is supported by four national technical assistance organizations. It was formed in 1996 to expand an already existing Peer Network formed by the Center for the Study of Social Policy. The Network was working to accelerate the development of comprehensive community systems for children and families. The newly formed component of the network specifically focuses on community services and supports for families with children suffering from mental health, behavioral, or emotional problems.

The four organizations that form this partnership for children's mental health are: the Federation of Families for Children's Mental Health; the National Resource Network for Child and Family Mental Health Services at the Washington Business Group on Health; the National Technical Assistance Center for Children's Mental Health at Georgetown University; and the Center for the Study of Social Policy. Participation in this work is made possible through funding from the Center for Mental Health Services, part of the federal government's Substance Abuse and Mental Health Services Administration, Pew Charitable Trusts, the Annie E. Casey Foundation, and the Packard Foundation. In addition to providing peer-to-peer consultation on clearly defined problems, the Peer Network is also beginning to publicize examples of emerging best practices in this arena through disseminating information on the most significant issues.

Simultaneous with the development of the Peer Technical Assistance Network, each of the partner organizations were discovering that their constituents — states, communities, and family advocacy organizations — were facing some major challenges with regard to the relationship between family members and professionals.

Despite long-standing recognition of the value of families and professionals working together as partners or allies, the practice was proving more difficult than anticipated. Families and professionals alike were experiencing unprecedented frustration in trying to make things work. There was broad recognition of the need to revisit some of the basic assumptions about these relationships. Accordingly, the partners in this endeavor recognized the importance of this challenging work and agreed to address it as the first "cutting edge" issue for its work. This work is a work in progress that reflects one point in time in an ongoing conversation among a group of professionals and family advocates who are part of the National Peer Network.

Five of us have served as the writing team to prepare this document. We have explored several different ideas, with a specific focus on power and empowerment, interdependence, mutuality, and reciprocity.

We have done extensive reading, engaged in numerous discussions, and participated in focus groups with family advocates. We have also been involved in intense exploration and discussion with the members of the Peer Technical Assistance Network. This process engaged us in the most open and honest dialogue many of us had ever experienced.

The members of our writing team included peer consultants, Jane Adams, Director, Keys for Networking in Kansas; Charlie Biss, Director of Children's Mental Health Services in Vermont; and Valerie Burrell Mohammad, a parent consultant in Richmond, Virginia; peer consultant trainers and partnership organization members Judith Meyers, and Elaine Slaton of the Federation of Families for Children's Mental Health in Virginia. We truly discovered the meaning of working in partnership -with all its joys and challenges - as we struggled to come to terms with the ideas presented here, and experienced moving far beyond any place we would have reached working on our own.

We would like to acknowledge the peer consultants who were part of this: Juanita Blount Clark, Raymond Crowel, Angela Diaz, Karen Gora, Susan Igneizi, Sylvia Johnson, Martha Kaufman, Carol Lichtenwalter, Joan Luzney, Neal Mazer, Gerald McKimney, Larry Michalczyk, Kathryn Nicodemus and Araminta Rivera.

The following staff from each of the four organizations made significant contributions: Barbara Huff from the Federation of Families, Connie Delimuth and DeAnn Lechtenberger from the National Resource Network, Joan Dodge and Sybil Goldman from the Georgetown Technical Assistance Center, and Frank Farrow and Jean McIntosh from Center for the Study of Social Policy. We would also like to thank Joceyln Martin from the University of Kansas Department of Social Work, who provided research assistance.

We present this document as the beginning of a conversation that we have come to believe is essential if the relationship between family members and professionals is going to thrive. We have found the issues not easy to talk about, let alone capture in writing. The relationship is constantly evolving and the associated feelings run deep. We do not pretend to have the answers, but hope this document presents a context and serves as a catalyst to promote further dialogue in many communities.

The Peer Technical Assistance Network plans to use this document in its future work and hopes it is useful to others in the field who are trying to further the development of services and supports to improve the lives of children and their families and communities.

Jane Adams  
Charlie Biss  
Valerie Burrell Mohammad  
Judith Meyers  
Elaine Slaton

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## CHAPTER 1: INTRODUCTION

While the concept of *family involvement* has for some time been considered tantamount to systems change efforts in the mental health arena, implementation of this into successful working models has been a struggle. Mandates from private foundations and federally funded grants call for local, regional and state programs to form *partnerships* with families in designing, implementing and evaluating services and supports for children and youth with mental health problems along with their families. Little evidence exists, however, of any highly successful or easily replicable infrastructure or implementation models of these types of partnerships. In fact, more information is available on what is not working. The communities which have embraced the concept of family involvement, and have made best efforts to operationalize and implement it, have discovered unforeseen challenges and faults in some of the basic assumptions.

For over a year prior to the inception of the Peer Network, the Federation of Families for Children's Mental Health created several focus groups and did extensive interviewing and experiential exercises. The outcome of this preliminary work was to shed light on existing models to determine what is working, what is not working, how we really want family involvement to effect systems change, and how we should focus the search for what would work.

We have learned that **organized** networks of families have worked most effectively in providing the infrastructure and supports necessary to bring the voices of families "to the table." We have also learned that particular traits of the people trying to partner with one another are critical to the success of this interaction. In addition, the language used to describe the goals, the anticipated outcomes, and the relationships between families and professionals is problematic and fraught with incongruent meanings, expectations and intentions. Accordingly, the very paradigm used in thinking about systems change and family involvement in that process needs to be revised.

What follows is a brief discussion about these points, an introduction to the rest of the manuscript, and, finally, strategies for improvement.

Three common denominators emerged in an examination of some of the first relationships where families were apparently effective participants in decision making about services, supports, systems and policies. (These interviews were from families and professionals in Kansas, North Dakota, Massachusetts, Rhode Island, and Vermont.)

- The relationship was formalized through contracts between the provider entity or the system agency and a family network organization representing the families who used or were at risk of needing to use the mental health system.
- The professional partners were deeply committed to the inclusion of families in decision-making. They worked well in diverse situations by utilizing specific skills to cross class and cultural boundaries.

- The relationship occurred within relatively “safe” social contexts with collegial-like interactions between the partners.

These three common qualities of successful partnerships — organized networks of families, committed professionals, and safe and rich relationships — provide directives towards the necessary elements of effective partnerships. (These elements, however, might not survive staff transitions as they are dependent upon particular personnel who are, as mentioned, committed and particularly well skilled.)

Similar examination of the neighborhoods, regions, and states that have been struggling to implement family involvement reveal not only very personal feelings of ‘danger’ but also the emergence of opposing definitions of key terms such as *family*, *involvement* and *partnership*, and of widely divergent implementation models that have been largely ineffective.

Definitions of family have ranged from a broad perspective wherein the structure is defined to include members of the extended family to one which involves only the biological parents of children with serious emotional, behavioral, or mental disorders. (The broader definition has resulted in situations wherein a system engages the mother of non-disabled adult children to represent what families need and want from public mental health programs.)

Similarly, there are many ideas about what constitutes *family involvement*. These conceptions range from situations where families are invited to serve refreshments at council meetings to others that mandate that a few of the program’s employees should have children with special needs. Another viewpoint is that families should be the power structure overseeing the system. Still another perception of *partnership* means that families should be expected to carry risk equal to that of the agency. Some families have interpreted their involvement to mean that no meetings should occur without their participation. By entering into partnerships with opposing sets of understandings, assumptions and expectations, most groups eventually experience a general sense of frustration and failure.

Some of the models that have emerged evolved to involve families have precluded effective advocacy by employing family members, thereby co-opting their allegiance and autonomy. Others have refused to engage with family organizations, choosing instead to invite one or two parent participants who lack a connection to a network of families. Confusion and conflict have arisen in communities where there are a number of family organizations and the system agencies have to determine which group to engage. And, in other situations, contracts have been written between family organizations and system agencies without sufficient attention to quality assurance, causing professionals to complain that they didn’t get what they paid for.

Perhaps the general failure to achieve effective family involvement is most evident in the personal frustration, fear and anger of the key players.

Family members veteran to systems change and “family involvement” have complained about:

- feeling exploited by provider organizations that use their support to win grants or request public endorsement of particular causes while failing to provide adequate



background information or to include families in decision making, planning, and implementing grant projects;

- feeling threatened by professionals who feel their status in jeopardy; and
- feeling intensely vulnerable when they are called upon to publicly share their personal stories for the sake of exposing system inadequacies.

On the provider side, professionals have complained about:

- fearing families will request more than the available resources can provide; in fact, perhaps more than anyone has the knowledge or capacity to provide;
- the impact that including families in their arena might have on their reputation among their peers; and
- feeling devalued as human beings when the systems change and family involvement discussions center on money and power, as if that is the sum of their value to the system

In point of fact, the overwhelming level of personal frustration and stress experienced by both professionals and families is drastically inhibiting reform efforts. ‘

This paper is based upon the predication that the very term *family involvement* is problematic. By introducing “systems thinking” into the model, a more relevant and effective framework can be established. This framework suggests that families are already critical participants in the ecosystem that raises and serves children. The task is not to bring families into an arena that they’ve not previously belonged to. The task is to fully recognize and honor the membership they already have — a membership that is absolutely central to the life of the child. Once this membership is acknowledged, the task is simplified. In short, it consists of creating linkages between all the members of the system -between the professionals and the families. Linkages, or “feedback loops,” are basic to the process of optimizing the role of every member of the system. That optimization is key to any system evolving toward its most effective functioning, and to the strength and sustainability of that system.

*“If it is true that a chain is only as strong as its weakest link, isn’t it also true a society is only as healthy as its sickest citizen and only as wealthy as its most deprived.” (Angelou, 1997)*

Reframed as a system’s issue — and not an issue of family involvement — the problem can be stated as a **failure to develop and maintain authentic customer/family voices to provide the necessary feedback loop for the creation and ongoing evolution of the system. Without feedback loops, ineffective and inadequate services and supports are designed and implemented. These systems are inappropriate and inaccessible.**

This paper is intended to challenge existing perspectives of the problem and the goal, to offer a new “world view” of systems of care from which new solutions may be discovered, and to provide preliminary direction to processes and necessary personal skills that should advance the interdependent relationships between professionals and families. We hope to change the readers’ thinking about every member’s role in developing effective and efficient systems which help and support children with mental health issues and their families.

Preceding Chapter Two, personal comments from a family member and a professional member of mental health systems are offered.

In Chapter Two, a more thorough examination of the risk perceived by the members of the systems highlights themes of mutuality and common vulnerabilities. Presented as mutual liabilities, these themes will actually serve to underscore the interdependence of all members of the system.

Chapter Three will examine the writings on the historical context of this work, which clearly indicate that the issues of power, control, and authority are critical elements in the difficulties concerning family involvement.

Chapter Four will examine systems theory as an alternative way to address family professional relationships.

In Chapter Five, readers will be presented with a continuum to determine their particular situation and to make decisions about where to go next and how to get there.

And, finally, this document will offer a series of strategies for building and maintaining feedback loops, interdependent relationships between families and all other members of the system for the creation, evolution, and sustaining of effective family/professional partnership systems.

Clearly, this paper — its discussions and recommendations — represent only a point in time. Most assuredly, as progress is being rapidly achieved in this field, the paper would be significantly different if it were written a year from now.

This paper is intended to be generic enough to be applicable across systems, disciplines and disabilities. Although written primarily through the lens of the mental health system, we hope that families and professionals connected to the juvenile justice, child welfare, education, health and other systems will find its contents useful.

## REFERENCES

Angelou, M. (1997). *Even the Stars Look Lonesome*. New York: Random House, p. 108.

## **FAMILY INVOLVEMENT: A PARENT'S PERSPECTIVE**

Valerie Burrell-Mohammad

*When talking about family involvement, family/parent advocacy and how to design that aspect of any team or partnership. Let's be mindful that all participants regardless of title or role deserve the same level of respect.*

*My experience has shown me that parental involvement is a very difficult thing to accept at times. I believe it exists for many reasons. As a parent/partners/consultant we are looked at as the one with the most needs. So it can be assumed in the collaboration process our input regarding what the service should be and how it should be served/delivered we have those answers. Beyond that, depending upon what group of professionals, your inputs into the process at that point becomes non-existent. My experience has caused me to be the star of the show and or the show stopper + /—.*

*And as a woman with discipline and dignity, it has been painful! These opportunities to serve and deliver in a better for children and families will never cease to exist. The need is great and at times it's easy to get frustrated and discouraged. Again with commitment and support that same situation has come through with hope and renewed pos-*

sibilities and opportunities. Life becomes better for everyone. The child/children/parents and professionals. Everyone realizes and accepts each other's position and role of authority, their knowledge base and experience in the process. Whether it is a mental-health crisis, IEP-Process, or a child with an illness. Each and everyone of us as adults have the responsibility of looking very clearly into the situation and doing our level best. As a parent in the process of creating systemic-change, I often question myself, my capabilities because I'm thinking, what professionals are thinking of me.

Questioning my skills and abilities, yet having me to believe they are not to be questioned or challenged. I have managed to stay firm and committed because had I given in or given up my power as a parent over, my child could have been seriously-neurologically damaged or dead! Yes there are struggles, but verily after every difficulty comes ease, after every difficulty comes ease! I encourage all partners to dig deep within oneself and extract the faith, perseverance, that we all need to continue in the struggle. My sincere hope is that we all genuinely, humanly with honesty continue to establish and build a sound foundation for family involvement. Being truthful to one another even when we don't know what it will require. Don't give others the impression your site or organization has it all, is doing it all, is grand and rare form. Don't

*allow your personal opinions and petty feelings about a person or group hinder the work, especially since we all declare it is far better outcomes regarding children and Family Mental Health! And above all remember that for some of us as parents in partnership, it's not the trips, financial incentive or recognition (to be seen among mankind). I realize that this is difficult, painful, laborious and time-consuming work. The families in these systems endure all of the above time and time again! We are facing the challenges and meeting the needs of our families and communities, one by one, day by day. Let us all remember we have the same goal, although we may have different experiences, different ways of verbally expressing it and different points of view. Accept it, respect it! A-C-C-E-P-T it, R-E-S-P-E-C-T it, and build on it!*

*"Unless you try to do something beyond what you have already mastered, you will never grow."*

*Bill Cosby.*

## **FAMILY INVOLVEMENT : A PROFESSIONAL PERSPECTIVE**

**Charles Bliss**

Meaningful family involvement is a simple concept that produces profound results. It starts from a place of looking beyond our roles and our credentials to finding the best way to problem-solve with another human being. It begins by developing a relationship of mutual respect, and means that we look at the whole person in tier many environments with an emphasis on getting to know them by the things that are going well and that give them hope. As a professional, I think our main strength is our ability to listen, really listen, and then really, really listen. Only then should we respond with messages of hope and liberation. This attitude will also liberate us to be more effective.

How do we develop or foster this attitude in real life and in real jobs, when systems, funding, credential, training, work environments, laws, rules, regulations, and even professional ethics create barriers?... Persevere and do the right thing!

## **CHAPTER 2: WHAT'S EVERYBODY SO AFRAID OF?: The Perceived Risks of Family Involvement**

Perhaps the most critical key to developing strategies for professionals and families to work together effectively lies in understanding why both partners feel it is dangerous, risky and intensely difficult work. Any partner's ability to be creative enough, committed enough, or persistent enough to overcome political, financial, and structural barriers obstructing the process needs some sense of safety.

Why is this work of "joining together" perceived as dangerous and hard? Using quotes from professionals and families involved in systems change, this chapter will underscore the inherent commonality of those fears. The common themes found in the quotes point to a sense of mutuality, to mutual vulnerabilities. It is just this mutuality which enables the establishing of a framework for building and maintaining working feedback loops between families and other members to create effective systems.

When professionals or families who are trying to partner at either the individual child and family level or at the policy setting systems level are asked, "What about family involvement are you afraid of?"

Families respond with statements such as:

- I'm afraid of losing custody of my child if I make too much trouble.
- I'm afraid my child's providers will be angry with me for speaking out and reject us.
- I am angry about being exploited — showcased every time the program goes after another grant. After they get the money, we never hear from them. And, I'm afraid that won't change.
- I'm afraid family voices won't make a difference. We've been asked to speak for a cause without enough information, but we're told what to say.
- I'm afraid of feeling like a failure when I speak out for other parents, but I cannot make things better for them.
- I'm afraid of being blamed for my child's problems.

Providers/professionals respond with such statements as:

- I'm afraid I'll have to answer to my boss for a decision I didn't make.
- I'm afraid of losing my professional identity — status — ownership of the expertise.

- I'm afraid no one will want the treatment I'm so proud to offer.
- If families takeover, we'll all lose our jobs, our financial security.
- If partnering with families doesn't work, I'll be seen as incompetent — and a traitor to my profession for trying.
- Things are changing so fast, I'm afraid I can't keep up. When families want so much so quickly, I'm afraid of not being able to deliver and being helpless and incompetent.
- I'm afraid a family will hurt their child and I'll be blamed for trying to collaborate with them.
- I feel families only see us as our roles — not as fellow human beings.

Six mutual themes emerge in analyzing all of the issues raised by the families and professionals we interviewed.

### **1. Fear of losing power and control.**

Almost everyone fears losing the power and control they believe they possess — or should possess. Professionals who are accustomed to being in control of their practice, program or agency are understandably concerned about losing that control and of being without the power base from which they do their work. Families who have been generally marginalized and powerless fear any further loss of control. However, a potentially serious mistake in responding to the power issue would be to replicate the existing imbalance of power in the system. By giving families all of the power over the professionals — to simply replace one power group with another — would not be a move toward mutual participation in the evolution of improved systems of care. Any group's power over any other group simply does not constitute an environment for partnership or for mutual participation in the system's creation.

### **2. Fear of having responsibility without authority.**

As responsibility is shared and shifted with new alliances and collaborations, there is fear that a participant will make decisions without having the authority to do so. It is imperative that the boundaries of the decision-making process be clearly outlined and accepted by all members of the group.

### **3. Fear of loss of personal and professional identity and value.**

As roles and responsibilities shift, members share a general concern about their own value in the process. The common theme shared by all participants is the general fear of not being valued as human beings.



#### **4. Fear of being seen as incompetent.**

Certainly, families who have children with serious emotional disturbances, children who have gotten into trouble with the law, or children who need special assistance of any kind are concerned about the “blame the family” mentality. They fear that professionals enter into the situation prejudiced by the assumption that as a parent (usually their most coveted status) they are less than competent.

Similarly, professionals are concerned that if they are not successful in treating the situation, they will be viewed as incompetent. Their lack of success, however, may be due to the fact that their resources are overburdened and under supported (the phrase, interestingly enough, generally used to refer to the conditions of families’ lives). All members consider being valued by another human being just as important as being considered capable of effectively handling their position.

#### **5. Fear of isolation — of being excluded**

Professionals cited a fear of being rejected by their professional peer group for participating in family involvement based programs. And, perhaps more than any other group, families of children with mental health issues already know the painful experience of isolation.

#### **6. Fear of a child getting hurt.**

*What if a child gets hurt?* Professionals asked what if a child is hurt by parents who have destructive or harmful behavior? Families asked what if a child is hurt by lack of appropriate services and supports, or worse yet, by professional practices born out of institutionalized racism? “But some families hurt their children” is the oldest excuse in the world for not engaging in family involvement. Yes, there are families who hurt their children. They are more often than not families who have been stressed without support beyond their resilience, who love their children and who are loved by their children. They are more often than not the very families these children will stay in contact with for their entire lives, outlasting by decades any contact with any single professional. And, there are clergy and therapists, teachers and scout leaders who hurt children.

A social worker was recently traveling through a small village in Mexico when asked through a translator why Americans hate their children. Even an elderly Indian woman living in a remote mountain village in another country has recognized that American culture does not care tenderly for every single child. The list of what seriously harms, maims and kills children is long — inadequate health care, starvation, poverty, racism and discrimination and on and on.

Rather than an excuse for not involving families, *consider that family involvement may be the best possible pathway.*

- toward helping families who hurt their children,
- toward stopping professionals who hurt children,
- toward finding resolutions for poverty,
- toward ending racism and discrimination.

These themes point to a significant mutuality in the vulnerabilities people feel as they enter into this new way of doing business. Everyone wants to feel valued, respected, competent, in control of their own “sphere” of responsibility. No one wants to feel powerless or manipulated. It does not appear that any of the partners wish for anything less than positive outcomes for children and their families. As communities implement and evaluate services and supports for children and youth, they must respect the humanness of all members of the system.

## CHAPTER 3: LOOKING BACK - LOOKING FORWARD

*“Parent involvement is not some kind of fad that will pass, it is the core of systems change. It is the only thing that can make true reform in human services possible.”*  
(Orrego, 1996)

Since the mid-1980s when the federal government first funded the Child and Adolescent Service System Program, terms such as family involvement, family-professional partnerships, family participation have defined the principles and values of including families as decision makers. Family participation was seen as vital to the planning and development of service systems, treatment options, and individual service plans for children with emotional and behavioral problems.

Historically, as we have pointed out, service providers viewed families as the source of problems, as obstacles to treatment, or as irrelevant to the treatment process. As the importance of parents as experts about their own children has been increasingly recognized and appreciated, the evolution of the role of families in systems of care has been expanded. The participation of families ranges from involvement in the individual treatment of their own children to becoming broader - service system designers in configuring best practices for children. Family members, who are consumers of particular services, now participate in policy development, planning, training, evaluation, and research. Family members have also become providers of services, such as respite workers and case managers. They have also assumed administrative and advocacy positions within government and nonprofit agencies. (Koroloff, Friesen, Reilly, Rinkin 1996)

Several changes over the past 13 years have contributed to the expanded role of family members in services for their children:

- Rapid expansion in the knowledge base which discredits theories of family interaction as the causative agent of emotional disorders in their children;
- Greater dissemination of knowledge and information to both families and service providers;
- Increased commitment to effective practice;
- A general rise in consumerism with an emphasis on empowerment and choice.

As professional knowledge about the importance and value of family provider relationships grows, recognition of the importance of the family context in serving children who have serious emotional and behavioral needs expands. In addition, family advocacy networks became more organized and influential.

Many challenges still exist, however, for both partners regarding the scope and nature of family involvement. Even as more states and communities are committed to and support the philosophy of family-professional

partnerships, the rhetoric often times far surpasses the reality. The implementation process is often fraught with difficulties.

We find ourselves at a critical juncture: While recognizing that even the most recent thinking concerning family involvement no longer applies, we have not yet adopted new language or frameworks that more accurately capture the essence of these relationships.

This chapter traces the changes that have occurred in the relationship between professionals and families in services for individual children and families, since the inauguration of Child and Adolescent Service System Program. It also focuses on the changes in the broader realm of family involvement in organizational and system-level planning and decision-making. This summary provides us with a context for understanding the progress that has been made, the lessons that have been learned, and the challenges before us.

Reviewing the written literature on family involvement has also helped us discover and resonate with certain concepts that seem to encapsulate what we are seeking — a new way of thinking about the relationship between families and service providers at both the individual family level and the policy level. This philosophy is one that emphasizes the interdependence of us all and the need to engage as allies in the struggle to improve the lives of our children. (The next chapter describes those concepts and their implications for families and professionals as we look to the future.)

### **Changes in the Role of Families in Service Delivery**

Over the past fifteen years, there has been a radical shift away from the traditional medical model in delivering services for children. The goal is for these services to become more family-centered and, as a result, more flexible. The services are designed and delivered according to the particular needs and preferences of the family members. They build on strengths and resources, rather than weaknesses and deficits. In this new partnership, the professional is no longer viewed as the expert and leader. The family caregivers are no longer just considered service recipients or informants. Both are equal partners.

### **Families as Partners in Service Delivery**

Building on their 1995 review of the literature on family-centered service delivery in the fields of health, education, and mental health, Allen and Petr at the University of Kansas' Beach Center on Families and Disability developed the following definition of family-centered service delivery:

*Family-centered service delivery, across disciplines and settings, views the family as the unit of attention, and organizes assistance in a collaborative fashion and in accordance with each individual family's wishes, strengths, and needs.*  
(Allen & Petr, 1995)

They found that the vast majority of authors described the relationship between families and professionals in delivering services as a collaboration or a partnership. The concepts of equality, mutuality, and teamwork were used to describe the nature of this partnership. Based on their theory, power and responsibility are shared by the family and the professional.

Both families and providers have the expertise to contribute to the helping process. While their contributions may be different, they are equally valued. In this partnership, professionals recognize the caregivers' experience of knowing the child and support their decisions about their own child. At the same time, Allen and Peter observe:

*Equal partners does not mean that parents and professionals assume each other's roles, but rather that they respect each others roles and contributions. While professionals bring technical knowledge and expertise to this relationship, parents offer the most intimate knowledge of their children, and often special skills.*  
(Allen & Petr, 1995)

From these observations, a summary emerges detailing the principles of best practice for professionals interested in a collaborative family-professional relationship. Their findings are augmented by DeChillo, Loren, and Mezera in a subsequent overview of both theoretical and more limited empirical literature on this topic. Taken as a whole, their work suggests that partners:

- Build on family strengths, while recognizing the family's limits and other responsibilities;
- Acknowledge families as the primary source of information about their children's and their own needs;
- Tailor services to fit the family's needs and preferences;
- Deliver services that meet the family's choices about the nature, timing, and location of services;
- Share up-to-date and complete information for families in an open and forthright way to enhance mutuality, confidentiality, timeliness, and completeness. This material should be presented to the family in their primary language, without the use of jargon, and in a variety of formats. Professionals need to provide information in a manner that allows parents to be informed and shape the decisions that are being made, rather than providing them with material merely for review and approval.
- Share responsibility and power in the relationship, including joint decision making and problem solving.

These two reviews also offered strategies for professionals to build and sustain relationships between families and professionals that included such familiar mechanisms as:

- Attending to pragmatic details such as timing of meetings, costs incurred, and coordinating with other demands in the lives of families with children with serious problems;
- Training and retraining staff and including parents as trainers;
- Including parents, children, and other family members as members of the service delivery team;
- Training parents as case managers;
- Mandating inclusion of families in policy development and review processes;
- Reviewing and modifying policies, procedures, and practices to maximize family involvement in the delivery of care.

DeChillo, et al. (1996) suggest that successful collaboration between parents and professionals involves a reworking of the concept of professionalism. They cite a 1994 study of collaboration that found that professional activities that conveyed empathy, support, and understanding appeared to be the most preeminent feature of professionals' collaborative relationship with families. While support and understanding are necessary, they are not sufficient conditions for collaboration. The authors suggest a redefinition of professional skills to include a new array of skills and abilities:

- The ability to promote inclusion of a wide variety of stakeholders;
- The flexibility to work with a broad array of service options and possibilities;
- The capability to consider a range of issues made more complex because of the addition of multiple viewpoints and opinions;
- Patience and forbearance.

The authors point out that these notions have profound and unsettling implications for traditional notions of professionalism. (Tannen, 1996).

### **Families as Customers of Service Delivery.**

In some communities, the evolution in thinking has moved beyond concepts of family-professional collaborations or partnerships where both parents and professionals have joint decision-making authority to one where families are the primary and ultimate decision makers in their child's care giving process. Professionals work for families, not with them. Families become customers of services, choosing among competing providers those who want to and do serve them well.

With access to the necessary resources of information and funding, families can define their needs and align services to meet them. They can use their resources to choose among providers and contract with them for the services and supports that will provide the greatest gains in the shortest time. As conveyed by Tannen, (1996):

*“An apt metaphor for this new paradigm of service delivery is the image of the family in the driver’s seat ... if one begins with the fact that the family’s life is at issue, then they have the right to be in charge. If they have the best knowledge of their own needs, strengths, culture, and goals, then their place is behind the wheel — in control. The service provider belongs in the passenger seat. After working out the route with the driver, the provider can hold the map and acts as a guide and support.. If we believe that families know what they want and need, and that professionals are consultants hired by the families to help them reach their goals, then we are creating the blueprint for a family-designed system of services.”*

Although this perspective is not consistently applied in practice across the nation, in some communities there have been genuine shifts in the lines of responsibility, authority, and control from the professionals to the family members. Families First in Essex County, New York, which opened its doors in 1992, is an example of a system that has transformed the traditional professional-client hierarchy by implementing a system that is designed, implemented, and run by families. (Cole, 1996.) Services are based on what people say they want and need. Among the principles recommended by a parent planning committee forming the foundation for Families First are the following:

- All committees have at least 50 percent parent representation;
- Preference in hiring for all staff positions is given to parents of children with special needs;
- Parents participate as trainers in training of all staff and volunteers;
- Parents establish criteria for family-friendly agencies and award those that meet the criteria a Family-Friendly Seal of Approval;
- Family members are given the opportunity to interview staff members and decide whether or not they want to work with them;
- Language that is respectful and inclusive of parents is stressed.

There are an increasing number of sites such as those funded through The Annie E. Casey Foundation’s Mental Health Initiative for Urban Children, the Robert Wood Johnson Foundation’s Mental Health Services Program for Youth, and the Federal Center for Mental Health Services’ Comprehensive Community Mental Health Services for Children and their Families grants, that are serving as laboratories for designing and

operating more stems in a way that seeks to recognize and support the increasing power of family members. (King, & Meyers, 1996)

### **Changes in the Role of Families in Policy, Planning, and Evaluation.**

As families gained experience in making decisions about their own children's care, they came to appreciate that participation in the larger service systems (community, state, and national) was going to be necessary to truly make a difference in the lives of their children and the children of others. While empowering individual family members in service delivery for their children was important work, it was not sufficient for producing structural changes in the service delivery systems and the policies and practices that were their foundation. Over time, family members became increasingly involved as members of various councils, committees, and commissions at the national, state, and local levels. In addition they have assumed new roles as grant reviewers, program evaluators and researchers, trainers, curriculum developers, and sometimes as agency staff or consultants.

Despite these advances, family members often did not (and still do not) find their input either valued or listened to. (Bryant-Comstock, Huff & VanDenBerg, 1996). They felt like token participants in these settings, largely because, in fact, they were. Family advocates came to realize that unless families were linked to each other by being organized, they would have little effect on changing systems. Their experience is reflected in Michelle Fine's lessons about parent involvement in another setting — the public schools:

*Rich and real parent involvement requires a three-way commitment - to organizing parents, to restructuring schools and communities towards enriched educational and economic outcomes, and to inventing rich visions of educational democracies of difference. Unless parents are organized as a political body, parent involvement projects will devolve into a swamp of crisis intervention, leaving neither a legacy of empowerment nor a hint of systemic change. Without a commitment to democratically restructuring schools and communities, parent involvement projects will end up helping families (or not) rather than transforming public life. Without an image of parents and educators working across lines of power, class, race, gender, status, and politics, toward democracies of difference, each group is likely to feel they have gotten no hearing, and will default to their respective corners shrouded in private interests and opposition. (Fine, 1993).*

The formation of a national family advocacy organization for children with serious emotional disorders was an early outgrowth of these experiences. Parents formed the Federation of Families for Children's Mental Health in 1989. Their purpose was to bolster their individual voices across states, to gather and disseminate information themselves, and to collectively address the needs of families dealing with emotional, behavioral, and mental health issues across child and family serving systems. Families wanted their own access to information and they wanted to effect national level policy and the development of those policies within the states.



*“In a relatively short time, the Federation of Families for Children’s Mental Health has become a national voice for children with emotional, behavioral, or mental disorders and their families. Whether through persistent lobbying efforts on Capitol Hill or providing input and guidance for federal activities, individual advocacy for families with state government officials, or one-on-one technical assistance to families interested in setting up family support groups, the Federation has maintained a high level of commitment to ensuring the betterment of services for children with emotional, behavioral, or mental disorders and their families.” (Bryant-Comstock, Huff, & VanDenBerg, 1996).*

Family advocacy organizations are more than just a collective of empowered individuals, though clearly that has been important to the movement. Their strength is in their collective power and action across organizations and across states. With the development of a grassroots family network structure, parents now have the same access as providers to information, resources, and support from other parents across the country. Within this network, parents from Virginia are able to compare and exchange information and secure advice from Georgia, Kansas, Montana, California, Vermont, and other states.

The Federal Center for Mental Health Services has provided direct support through five year grants to state-wide family run organizations. These grants assist in providing information and support to families whose children have mental health concerns. In the last two years, the focus has grown to include developing strategies to engage the family voices in the development of managed care initiatives (1996-1998). Many states have also contributed funding for this purpose.

Today, family voices at the national and state policy level are being heard. However, translating this experience to the local level, is still very difficult. Changes in thinking, attitudes, and practice are seen more often both at the top levels of policy making and at the individual family level. Family advocates report that, at the middle management level, there has been relatively little change in how families are viewed in this effort.

As stated earlier, this is the opportune time to develop links between families and professionals. Experience in communities that are genuinely committed to the principles of family involvement are teaching us that effective family participation in systems of care for children requires a new way of thinking about roles and relationships between family members and providers and policymakers. In the next chapter we formulate what these new relationships might look like and explore some new ways of thinking about issues of power, resource sharing, and interdependence.

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## CHAPTER 4: NEW WAYS OF THINKING AND WORKING

*Only by changing how we think can we change deeply embedded policies and practices. Only by changing how we interact can shared visions, shared understandings, and new capacities for coordinated action be established. (Senge, 1994).*

Our search for a new way of thinking about the relationship between family members and professionals grows from the realization that our current frameworks do not serve us well. Although we have come a long way from the days of “blame and shame” to “partnerships”, we are still not there. When we listen to family members, providers, policymakers, and system administrators discuss the issue of family-professional partnerships, we continue to hear deeply felt feelings of frustration, anger, and pain.

As already stated, there has undoubtedly been more progress in rhetoric than in actual practice. As many times as values and principles are developed and disseminated, stated and restated, they still are not widely recognized and applied on the front lines. It is not clear that finding yet one more paradigm with new rhetoric is the answer. On the other hand, if our current language, ideas, and practices are outdated or inadequate, we believe we must continue the search to find the particular frameworks that come closest to reflecting our reality. We will use those as a basis for designing new strategies.

This chapter shares where this journey has taken us. Our goal has been to determine what system best captures a framework of relating between family members of children with serious behavioral and emotional problems and the state and local professionals who work with them.

The significant role that power plays in the current struggle in the relationship between families and professionals was evident to us almost from the beginning. Of particular significance was the commonly held belief that power is not equally distributed across groups. Family members rarely share the same access to power as do providers or policy staff. This leads to feelings of fear, distrust, anger, and competitiveness.

To gain a better understanding of the dynamics of this relationship, we initially focused on the concept of power and how it plays out between family members and professionals. The writings of Barr and Cochrane at the Cornell Family Empowerment Project and the work of the Family Resource Coalition helped shape our thinking. We noticed that different forms of power were in evidence.

The notion of power as one group having control over another within hierarchical systems was destructive to relationships between families and professionals. Power that they shared within a network, however, was constructive.

The more we discussed the role of power the more we realized that understanding its role was only the first step in advancing the state of relationships between family members and professionals. By bringing the discussion of power out into the open, we could move toward a concept of relationships based not just on recognizing the sources of power but relationships that reflected mutuality, reciprocity, and interdependence.

Readings by a number of authors in a wide range of fields, including science, management, leadership, and service systems reform, seemed to be pointing in this same direction. There seemed to be a convergence of thinking based on a systemic or ecological framework that centered on the notion of interrelated systems or networks. Within these networks, everyone and everything are understood to be part of a larger system.

We find ourselves resonating with that thinking in our own pursuit. If we are to realize the potential inherent in relationships between family members and professionals, it is important to recognize that neither group can accomplish its mission without the other. *All players are a necessary part of a whole, with each bringing their own special set of skills, knowledge, and experience to the table.*

In this section we will share some of our discoveries about power and about systems thinking. We will then present what family members and professionals each contribute to the system and the supports they need to be engaged and effective contributing members. (This will form the context for a discussion of strategies presented in the last chapter.)

### **The Role of Power in Family-Professional Relationships**

Power itself is neutral, neither good nor evil. Yet it is a word that often makes people very uncomfortable. Power has the potential to be divisive and is not easily or openly discussed. We raise the issue of power not with the intent of promoting conflict in the struggle among families and professionals. Rather, we want to suggest that an understanding of the inequities in the relationship between these groups will lead to a better understanding of how the relationship has worked (or not worked) and how it can be improved.

The evolution of family involvement in systems of care has, in part, been an issue of shifting power, power which has not been equally distributed across groups. Even our use of the term “family involvement” connotes something about the balance of power. Who is truly involving whom here? Why don’t we call it “professional involvement? When we begin to describe these relationships as collaborations or partnerships, we are conveying more equality. Our intent is to open up discussions of power and to move the issue from the hidden or unspoken domain into a conscious and public forum.

Power is defined in a variety of ways. Two of the definitions of the American Heritage Dictionary of the English Language (1992) suggest quite different meanings. One is “the ability or official capacity to exercise control; authority.” The other is “the ability or capacity to perform or act effectively.” There is a great deal of difference between these two definitions. Don Barr, of the Cornell Family Empowerment Project, notes this difference in his distinction between “power over” and “power with.” (Barr, 1995).

“Power over.” When power is exerted by one group over another, it becomes problematic. Those in power have the benefits of controlling access to valued resources, the ability to make more choices and control the choices of others, avoid accountability to those with less power, and get their issues on the agenda. Those with less power have little access to resources, have difficulty getting their issues on the agenda, and are often more accountable to those in power.

“Power with.” On the other hand, “power with” allows people to work together to find ways to satisfy their interests without imposing on each other. In these relationships there is a constant struggle for equality., “Power with” grows out of human interconnections within communities. Rather than a zero-sum game of win/lose, power is shared and involves a win/win outcome.

*“In contrast to the individualistic, dominating, hierarchical, and contested-terrain principles of power over, the alternative power with view is grounded in principles of community, interdependence, sharing, and non-hierarchical decision making.” (Barr, 1995).*

Power Over	Power With
Self interest	Community interest
Winning	Cooperation
Controlled access to valued resources	Shared access to valued resources
Hierarchical thinking structure	Nonhierarchical thinking and structure
Controlled participation	Open participation

For a variety of reasons — historic, cultural, social, economic — our service systems have been constructed so that professionals are perceived as having power over family members along with their children as users of their services. Professionals have more access to such resources as political power, purchasing power, information, education, and the benefits of social status. Family members often feel depleted of financial, emotional, political, and informational resources. Consequently, they experience very little control over their lives, or the lives of their children, when they seek help in the care and development of their children with serious behavioral, emotional, and cognitive difficulties.

The ideal situation in the relationship between families and professionals would be one where no one group has power over the other. The power would reside within the system, with both groups working together to enhance the their effectiveness.

### **The Interdependence and Interconnectedness of Families and Professionals**

As stated in the first chapter, when professionals begin to recognize what family members already know - that families are critical participants in the ecosystem in which children grow — the challenge is refrained. It no longer makes sense to think about how to bring families into an arena to which they already belong. Once everyone fully recognizes and appreciates the membership they already have, the task becomes one of how to develop and maintain authentic connections. Connections between families and all other members of the system, including professionals — or between professionals and all other members of the system, including

families. In a systems view, in which all life is seen as connected, all members, groups, and organizations of a community are interdependent. “The success of the whole community depends on the success of its individual members, while the success of each member depends on the success of the community as a whole.” (Capra, 1996).

In more fully exploring the theoretical concepts and ideas that support an interdependent approach, the works of Fritjof Capra, Peter Senge, and Lisbeth Schorr were especially helpful. Capra differentiates the old way of mechanistic thinking and the newer way of systems thinking in a way that mirrors the notions of “power over” and “power with” presented earlier. Mechanistic thinking is grounded in hierarchical structures, with leadership emanating from the top down, and often resides in one person who has more power than others. In systemic or ecological thinking, networks are key. Power comes from anywhere in the system and is conceived of as influence of others. Connectedness and relationships among the parts of a system are vital to its survival. The essential properties of a system arise from interactions and relationships among the parts. Members of the system collaborate, cooperating to achieve their ends. There are no hierarchies of systems, just networks nesting within other networks in a web.

The basic principles, outlined by both Capra and Senge, for building sustainable systems include interdependence, the cyclical flow of resources, partnership, flexibility, diversity, and, as a consequence of all those, sustainability. These principles apply to our work of building sustainable systems of care for children, their families, and communities:

- I. Interdependence. All members of a community are interconnected in a vast and intricate network of relationships from which they derive their essential properties. Therefore, they are mutually dependent on one another. The success of the whole community is dependent on the success of each member and the success of each member depends on the success of the whole. Nourishing the community means nourishing these relationships.
2. The cyclical flow of resources via feedback loops. The effects of actions, decisions, and behaviors in a system are not linear cause-effect chains, but rather ripple out in ever widening circles in the community. Actions reinforce or counteract each other through patterns of change that recur again and again. There is a reciprocal flow of influence so that every influence is both cause and effect. Nothing occurs in only one direction. As a result, everyone shares responsibility for problems generated by a system.
3. Partnerships. Partnerships are the tendency to associate, establish links, and cooperate. They are essential for sustaining a system. Partnership arrangements ensure democracy and personal empowerment because each member of the community plays an important role. As partnerships evolve, each partner better understands the



needs of the other. This results in both partners learning and changing. Cooperation and partnership replace competition and domination.

4. Flexibility. Because conditions are continually fluctuating, ecosystems survive by maintaining a readiness to adapt to changing conditions. Prolonged stress results from rigidity, or lack of flexibility, and can destroy the system. Flexibility also helps a system resolve inevitable conflicts.
5. Diversity. Diversity also helps a system to be resilient because it consists of members with overlapping functions and multiple approaches to problem solving. If a system is challenged, it will have numerous options for adapting, interpreting, and learning. According to Capra

*“...diversity is a strategic advantage only if there is a truly vibrant community, sustained by a web of relationships. If the community is fragmented into isolated groups and individuals, diversity can easily become a source of prejudice and friction. But if the community is aware of the interdependence of all its members, diversity will enrich all the relationships and thus enrich the community as a whole, as well as each individual member. In such a community information and ideas flow freely through the entire network, and the diversity of interpretations and learning styles — even the diversity of mistakes -will enrich the entire community.”*  
(Capra, 1996).

Flexibility and diversity go hand-in-hand in protecting systems from disturbances and serious challenges, allowing the system to adapt to changing conditions. Managing a system using these two principles means optimizing the functioning of each member without maximizing any single one at the expense of the others.

These theories, which emanate from science and management, support our call to refocus the way we think about relationships between families and professionals. We presuppose that a community’s strategies for involving families in operating and reforming systems of care will be more successful if they are based on these principles. Rather than seeing “families” and “professionals” as isolated singular parts who work independently of one another, we begin to see each as associated parts of a larger integrated whole. Rather than in competition with each other for control of scarce resources, where if one side gains the other loses (be it power or access to resources), they are interdependent, The values of cooperation and partnership become central to survival of the common good.

In the next sections we will consider the implications of systems thinking for the role of family members and of human service professionals. We will examine what each brings to the system, what each needs to function as an effective member of the system, and the benefits each will derive. In the end we see this approach as resulting in a win/win for everyone professionals, family members, and the ultimate beneficiaries, the children.

## Implications for the Role of Family Members

### *What Families Bring.*

As described succinctly in a publication of Keys For Networking, the statewide family advocacy organization in Kansas, “Family involvement throughout the planning and delivery of services benefits the child and makes the job easier for the professionals who provide services.” (Adams & Cooper (1995). The authors summarize these contributions which include:

- A perspective along with important information which is unique in its comprehensive and holistic approach. Family members assimilate multiple assessments, monitor multiple interventions, oversee daily living, implement 24-hour crisis intervention, and advocate for all their child’s needs. They usually know best what works with their child.
- Communications that are free of jargon and may help professionals from different disciplines talk to each other.
- Knowledge and understanding of the strengths and needs of family members, which may be vital to the success or failure of a treatment plan.
- An emotional investment that can rarely quit at the end of the work day or work week. Any service provider is ultimately transient in the life of the family, in a given day, week, month, or year. Family caregivers rarely are.
- Ability to monitor progress or relapses. Family members are on the front line when the child begins to relapse; they are the first to notice when the child improves. Family members are in an ideal position to help monitor the child’s response to medication.
- If they are satisfied consumers, families are the best advocates a public agency can have. Family members do not operate under the same legal and institutional constraints as professionals. With support and encouragement, they can become powerful voices in helping to support system developers and community projects. Families can generate the funds and public commitment by articulating the value of services and encouraging long-term community commitment to realistic initiatives.



We were reminded of the critical importance of some of these contributions all too vividly at the very time we were writing this paper. At the time, the National news was widely covering the story of a young man of 15 in New Jersey who murdered an 11-year-old neighbor who had come to his door to sell items as part of a school fundraiser. Only days prior to this tragedy, his parents had begged the court to place their 15-year old in a residential treatment facility because they recognized his behavior as dangerous. The professionals determined, however, that he was not a danger to himself or others and was capable of living at home with the support of outpatient counseling. Clearly, his parents knew better. If they were part of a system that recognized and valued their expertise as equal to that of the “professionals,” the results would have been quite different.

### ***What Families Need.***

To fulfill their partnership roles effectively, however, family caregivers need the following from professionals and other families: (Adams, Cooper, 1995).

- non-authoritarian help
- training
- information in a timely, straightforward, and accessible fashion, free of jargon and acronyms
- opportunities to exercise their management skills
- safety, closeness, and appreciation
- expressions of opinion and emotion
- acceptance of their diversity
- access, voice, ownership
- respect

### **Implications for the Role of the Human Service Professional**

#### ***What Professionals Bring.***

Professionals bring the following to the relationship with families and to the broader system: (Cornell Empowerment Group 1989).

- A body of knowledge that draws on well-developed and systematic theory about symptoms, causes, psychosocial or medical interventions, and medications for children. They are trained to help family members develop their own problem solving, behavior management, and stress management skills.

- Legitimacy and society's sanctioning of their work. Legitimacy is granted through registration, certification and licensing to those properly educated, trained, or credentialed to participate in that professional enterprise. They are therefore in a position to eradicate outmoded ideologies that promote family blame and power inequities, and help establish a new way of thinking that better serves children and their families.
- A code of ethics which gives them the power to set standards of acceptable professional behavior. These codes of ethics offer protections to family members, such as those regarding confidentiality.
- Control over certain resources.
- A culture that includes their own values, norms, symbols, and language. Culture mechanisms operate to recruit, screen, and socialize members of the group while also controlling the rewards of recognition and status. This allows them to perpetuate themselves, defining who is "in" and who is "out." Professionals can make the transformation to defining family members as "in" rather than "out" when they recognize the value family members bring to the larger system and the professionals' dependence on them for success.

### ***Professional Competencies Needed.***

For professionals to make the transition from a traditional, hierarchical way of relating to families to a more mutual and interdependent relationship, they will need to augment their skills as traditionally defined to include a new array of skills and abilities. These include: (Barr & Cochran, 1991).

- ability and commitment to identifying strengths in people and groups;
- genuine respect for diverse perspectives and lifestyles;
- ability to promote inclusion of a wide variety of stakeholders;
- a capacity to listen and reflect;
- the capability of considering a range of issues which become more complex due to the addition of multiple viewpoints and opinions;
- empathy — the capacity to view, value and appreciate the perspective of another;
- intuition and ability to synthesize;
- an ability to subordinate one's own ego (to put oneself aside in the interest of the group);

- skill and creativity in helping people become more aware and confident of their own abilities;
- appreciation of when to step back and the ability to help the individual or group assume decision-making and take action;
- ability to analyze power relations and help others to do so;
- knowledge about how to gain access to information;
- ability to reflect on and criticize ongoing processes, including one's own role in those processes;
- the flexibility to work with a broad array of service options and possibilities.

*For families and professionals to work together as equal partners, we have to stop dividing the world into “helpers” and “helpees” as though these represented two different species. It is time to acknowledge that stressors like substance abuse, loss, illness, divorce, and mental illness occur in the lives of professionals as well as clients. They, too, can have children with emotional problems. We all are subject to the human condition and all have the same needs for comfort and hope when we are struggling. (Tannen, 1996)*

Barr and Cochran, and Shorr, point out that individual professionals who are seeking to utilize a more systemic world view in the confines of a traditional bureaucracy, may find it very difficult. While dedicated to their vision, the structure, history, and culture of most service systems put them at risk of becoming part of the process of reproducing the status quo. This is contradictory to a systemic way of thinking and working. The bureaucracy gives them little freedom of movement. As Shorr writes, “We are so eager as a body politic, to eliminate the possibility that public servants will do anything wrong that we make it virtually impossible for them to do anything right.” (Shorr, 1997). In her recently published book *Common Purpose*, the chapter “Taming Bureaucracies to Support What Works” provides an in-depth look at why bureaucracies are dysfunctional. In their zeal to balance equity, quality, visibility, and accountability, they preclude flexibility, discretion, responsiveness, and effectiveness. At the same time, she also has hope for transformation, due to inspiring situations where bureaucracy has been tamed to allow new flexible and creative models to evolve. These examples remind us that there are opportunities every day within bureaucracy for professional staff to make decisions to promote policy and practice that supports family alliances.

An the majority of places where these changes have not taken root, the problem has been the marginalization of professionals who are attempting to transform their relationships with families while working within the system. They are often viewed as being at odds with the social service, educational, and political institutions they are working in. Barr and Cochran observe, however, that accepting that role frees the helper to share power — and accept help in return.

*When human service agencies ... try to create alternative uses of power by incorporating more democratic practices, they are fighting an uphill battle against old and entrenched structures and habits. This struggle is the center of the empowerment process because without a transformation of power over there is no empowerment process. This will be a long struggle and participants in it will only be able to see tiny steps in the desired direction because the challenge is formidable. (Barr, 1995).*

Some of the changes in the bureaucracy that would support a different way of working would have to include:

- Administrative support to more actively engage family members;
- Programmatic and fiscal flexibility to develop comprehensive service plans based on family needs rather than services available;
- Training to shift from staff-dominated to family-centered approaches;
- Leeway to create opportunities, provide information and training, and offer concrete support services to families;
- Time for professionals to communicate with families and other professionals;
- A system that makes them accountable, not in terms of units of services provided or individual activities undertaken, but rather by outcomes, by how skillfully they have engaged others in developing and implementing successful solutions. (Adams, Cooper 1995).

## **Conclusion**

We do not believe that adopting a “new way of thinking” that includes new language, ideas, competencies, and understandings is enough to make change happen. We do, however, believe it is an important and necessary step. As Tannen observes:

*Providers and consumers have traditionally been in a hierarchical relationship. As in any grass roots movement in which the underclass demands more power, few of those who have held the power willingly give it up. For those who are engaged in making this transition, it is important to identify allies, to get support wherever one can, to recognize that change takes time, and to have faith in the process. It is crucial to instill hope in families and providers, so that they can form an alliance for change rather than succumb to despair. (Tannen 1996).*

We are redefining the challenge to reframe the relationship between families and professionals. The relationship can no longer be based on power struggles between families and professionals. It has to be a mutual relationship, characterized by interdependence and cooperation. One of the philosophical underpinnings of the Federation of Families captures this concept, suggesting that perhaps family members have understood this for a long time, and it is only now that the providers, administrators, and policy makers are realizing its import:

*The greatest challenge to both families and professionals is that they must dare to dream and hope about what might be for children and adolescents with mental health disabilities ... Families and professionals must work together not only to improve services but to change the values and attitudes of society toward children with emotional, behavioral, and mental disorders. Families and professionals must dare to challenge perceived limits and actual barriers that are erected by systems and society.*

*Families and professionals must be willing to dream and take risks that will improve the quality of opportunities available. Without dreaming and risk-taking, full citizenship for this population of children and adolescents will not be achieved.*  
(Federation of Families for Children's Mental Health).

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## CHAPTER 5: CONTINUUM OF FAMILY-PROFESSIONAL RELATIONSHIPS

There have been dramatic changes in the past 13 years in the overall practice of children's mental health services. The most significant changes are evident in the services with individual families and systems level policy. Planning has evolved from an expert driven, professional-centered approach to family-centered, team-supported infrastructures. These infrastructures develop and support interdependent relationships and interlocking services.

States and communities, however, are each at their own point of development in this evolution. Some have achieved far more progress than others. We have tried to portray the stages of development in the form of a continuum. As readers begin to consider strategies for moving further along, they can use the continuum to determine where they are in their own development.

The stages are not discrete. A particular community may be further along in some aspects of this work than they are in others, but the process reflects progress as one moves from one stage to the next. Each stage involves a stronger commitment to thinking and action. As a result, the evolving family-centered approach has a solid foundation as it moves through the developmental process.

Acknowledging that individual service delivery and system planning issues interact - one strongly influences the other - we have combined attention to both. Families who receive services in a system that is strongly professional-centered bring that experience with them to system planning meetings. Their experience shapes their thinking, expectations, and behavior. The same is true for providers, who also behave from the framework of their experience. This may not be experienced as problematic when families and professionals come with similar frameworks. When their experiences are different, however, there may be "culture clash."

When invited to a stakeholder meeting where providers are more family and/or team centered, family members who are accustomed to a professional-centered model may act out what they have come to expect. This can potentially "put off" professionals who are there to listen to them. Likewise, when families with experience in family-centered systems come to meetings, their level of interaction and involvement may confuse professional-centered practitioners who aren't used to dealing with vocal, strong family representatives. The culture of individual services shapes the culture of the planning as do planning experiences shape individual child practice, for both families and providers.

Table I presents the stages of the continuum. The remainder of this section describes each level in more detail with a few case examples. Each of these examples (names are changed), represents the core of real situations presented to Kansas Keys for Networking, Inc. in the last three months. Table One shows the progression.

**CHILDREN AND YOUTH  
THE CONTINUUM OF SERVICES  
TABLE 1**

<b>Professional-Centered</b>	<b>Family-Focused</b>	<b>Family-Allied</b>	<b>Family-Centered</b>	<b>Team-Centered</b>
<p>On one end of the family service continuum is the professional stance that considers the professional to be the expert and views the family as a hostile resistive force in the way of achieving professional goals. The professional-parent relationship is unfriendly, viewed as adversarial, with the parent as the problem. This attitude results in the view of the family caregiver as someone who can be taught or treated. The parent must adapt to the professional's service values.</p>	<p>The professional philosophy views the professional as expert with families as helper and allies to the professional. The professional knows best and the relationship to the parent is one of getting the family caregiver to become a partner in helping the professional. The caregiver is "one down," because the professional decides the rules and roles, and the caregiver is merely and agent of the professional.</p>	<p>Families are viewed as the customer in the service delivery system. Professionals strive to attune the services to the needs and desires of the family who is their customer. The family caregiver is seen by providers as an equal colleague, one who has expertise, knowledge, and choice. Professionals and caregivers work collaboratively to address mutually-agreed upon goals.</p>	<p>Practice at this level of the continuum puts professionals "one down" to the family caregiver. The philosophy is that parents know what is best for themselves and their children. The philosophy is that professional's services exist to support parents as the primary agent in helping the child achieve his or her goals. The family is seen as the employer and the professional as the employee. The professional asks, "How can I help you? How can I be of service to you? What do you need?"</p>	<p>The wraparound model centers decision making with the team. Team strengths and resources (which include those of the provider as well as family and child) are collected and used to select intervention most likely to work. Both planning and intervention rest on the combined skills and flexible resources of a diversified committed team. Responsibility for decisions rests with the collective power of the team working together, supporting each other as well as supporting the family.</p>



## Professional-Centered.

In a professional-centered system, the agency works only with the child. Staff write treatment plans based on office interviews. Usually, a single agency, or an agency operating alone, provides services to meet identified deficits. Usually, the involvement of another agency includes formal requests for records or a request to attend a meeting. Plans are never developed between agencies. The family may end up with three different plans.

Parents are simply not included in planning, delivering interventions, or evaluating their effectiveness. Parents are not asked what they need to help their child. They are rarely seen as a resource, and never as the primary agent of twenty-four hour care. Providers at this level view the family as part of the problem, if not the very cause of it. Juvenile justice and child welfare programs are frequent examples of this level of practice.

One mother's attempt, for example, to recommend medications for her child who was incarcerated at a juvenile detention facility was dismissed by the youth services officer with, *"We take all youth off medications here. With our structured environment, he won't need his medication. Call back in a month to see if his behavior improves enough for you to visit. He must be on Level 3 before he can visit his family. And yes, his projected date to return to your home is still only two months away."*

*Another example is the therapist who tells the caregiver, "I cannot share any information with you. My relationship with your 14-year-old son is confidential. Sign this release, though, so I can request information from other agencies, which I cannot share with you." One Kansas mother's response to this level of help was, "I take this child home, knowing I cannot control him even through dinner and the therapist is discussing his issues with his father who abandoned us eight years ago. I need help for tonight. My son is now convinced my husband and I caused his problems."*

Providers make the decisions, know the "right" answers, and determine treatment. They work primarily from charts and other documents transferred from provider to provider. Providers frequently become frustrated and ineffective, perceiving family caregivers as unwilling and/or unable to do what they are told. They perceive the family caregivers as persons who won't get it right, won't follow through, and won't be consistent.

Family involvement in service and policy planning at this level doesn't happen. If it does, it doesn't go well. Providers experience families as fickle, non-compliant, non-committed, uninformed, angry, hostile, often aggressive, definitely resistant. Providers who attempt to plan with families who have been served at this level of practice find themselves defending the involvement to their colleagues, who say "Why do this?" Frustrated by the expense of providing childcare, transportation, lodging, up-front stipends to caregivers who appear ungrateful, they frequently decide that costs outweigh any long-term benefit to the agency or to the planning process.

At this level of practice, the child may become confused. Witnessing the blaming, the anger and tension as it shifts between parents and providers, he or she learns not to trust parents or providers. He or she hears

providers telling their parents they need therapy, parenting classes — does this mean they cannot parent? When the caregivers become overwhelmed, the youth may even hear discussions related to whether out-of-home placement is needed because their child's needs are too great for the community.

### **Family-Focused.**

In a family-focused system, providers recruit family members as helpers and allies in the child's treatment. The provider still knows best, determines the plan of care, and shares it with the family members.

Once the family requests help at this level, providers meet with them to determine their need for services. When the need for help involves more than one agency, many professionals become involved. This creates a situation where very personal problems are examined and shared across agencies. Involvement in the treatment process changes the family's role in the community.

They see themselves and their providers see them as needing help, wanting advice, direction, and guidance for the child. By accepting help, family caregivers come to see themselves as people who need to be helped, can expect to be judged as good or bad, and need teaching and advice. (Gleidman, Roth 1980).

What they receive, however, rarely matches their defined needs. This is especially true when their racial, gender, cultural or socioeconomic background is different from the provider community. Families get discouraged and angry because the provider recommendations don't really work; family members can't make them work. Yet, to get services, even services which they may not even see as very helpful, they must follow certain rules and wear the demeanor of a person needing help, of a person being helped. They learn to act dependent and passive with their caregivers. Helplessness, learned helplessness, frames their role, which becomes one of need. (Harry, 1992).

Families in this situation feel they are under the scrutiny of providers who are searching for their deficits. They feel they are being placed in the same status as the child who needs help. They learn to accept that they themselves should seek therapy or enroll in parenting classes. (Gleidman, Roth 1980). They begin to accept the judgments of the providers who assess how well the family follows the rules set out for them - if they meet appointments, if they follow the reinforcement schedule established by the therapist, if they make the child complete the homework set by the teacher, etc.

These judgments are passed from provider to provider and are based on the perceptions, values, and standards of people who are essentially strangers of the family's own values, culture, and beliefs.

At planning meetings, the family's experience, as well as the experience of most providers (other than those at the very top), is informal. It is limited to "input." Families may experience opportunities to learn and to attend meetings, but they get frustrated and discouraged by too much or not enough information, by complex and bureaucratic mazes. They find they cannot attend enough meetings to be effective. Work and child com-

mitments prohibit their real involvement. Furthermore, the families who attend such meetings are frequently not representative of the customer group—the actual service client whose issues are being considered. There has been no formalized process for selecting or recruiting families. The families represent no voice other than their own at the meeting. They are not accountable to any larger group of families for what they say.

This approach may actually increase the isolation of a child who becomes the target of a strangers intervention, one which the family only rarely can deliver to the satisfaction of the provider.

*Susan called the local hotline for help. She believed her adopted son, 12, was molesting her two small daughters. She has six children. She is physically ill herself and her husband works nights. Sixteen months later, staff from four agencies and three advocates have visited her home, have assessed the situation for possible parent abuse, and have advised her to build more structure into her discipline. At the direction of the mental health center, Susan and her husband have attended 13 sessions of couples counseling, and her adopted son and one daughter are now in therapy. She has yet to receive any of the supports she requested, i.e. attendant care.*

### **Family-Allied.**

In this situation, providers meet with family members and invite them to join the service planning process as equals. They are to become partners in determining what services their child will receive. Providers and family members make decisions together, but there are an endless series of meetings. Although collaboration is the priority, providers from different agencies inform families separately about what is available and what is not, one agency at a time.

Providers support what the family wants, what family caregivers say they need. Yet, the family frequently doesn't have enough information about services or enough contact with other families to know what to ask for. Since they don't know what to ask, they say "nothing."

Providers listen and search for services to match family needs. The provider still operates in the "I have it. I know more. I'll get it for you" mode. The family still operates from the "I need whatever you tell me I need" mode. When providers and caregivers figure out what the need is, maybe with a parent support consultant who is experienced with the service array, the relationship becomes more equal. Connecting with other parents who have secured services, who know the score, who can make suggestions and give advice from similar perspectives, encourages providers to focus on concerns and priorities of the whole family and encourages the family to request help rather than assume helplessness. Listening to family members concerns, empathizing with them, spending time with them, sharing common experiences with them, facilitates the family's ability to express their preferences. This assists them to best meet the needs of their child and family. Families want professionals to be sensitive, non-judgmental, and accepting of their diversity.

When providers are very good, the family allows services in their home, expects services, and eventually demands services. Entitlement issues develop. Sometimes families look to these providers for interventions,

for crisis help, for emotional support, and friendship. The family moves from independence to dependence to keep the relationships going. At this level, providing emotional support and maintaining professional distance is a challenge to many providers. Their training programs and service supervisors caution them against becoming “friends” with their clients and advise them to maintain a professional distance from those with whom they are working. (Turnbull, Turnbull, 1990).

Relationships are collegial. People are usually very friendly. Family caregivers understand when services are delayed or denied. Providers honor the efforts of the family and respect the limits of partner agencies. Should the family become displeased, advocacy efforts will come from outside the multi-partner group because locally everyone values preserving the community relationships. Getting along is the priority. At this level, family members worry about asking for too much, too often. Providers work more to collaborate with partner agencies than to help families secure services from those agencies. Everyone is respectful that there is not enough money to go around. People know each other, have worked together for a long time, and expect to work together in the future for a long time.

At the systems level, everyone knows each other. Nice, behaved, respectful families are welcomed as stakeholders to provide input on committees. Demanding, aggressive requests for services for specific children, high expectations for service delivery, and specific outcome monitoring are banished by the culture of the alliances between specific providers. They also don’t exist between agencies and even between individual families and their providers. Planners invite only families who are satisfied. Rarely are the customers of the specific services addressed. Even more rarely are they representative of the minority demographics of the population actually served.

*Kathy quits her job to oversee the care of her 14-year-old son who is being released from the state hospital. With an advocate she meets with mental health staff, educators and child welfare to identify financial supports and necessary services. The meeting lasts for hours. Everyone explains to Kathy that the services she seeks are just too new, they are not yet available. Within 48 hours, two of the three agencies call the state advocacy organization to secure help for her from the other agencies. Other local people say they cannot be involved in this advocacy effort. They state they must maintain their professional relationships but really want to help Kathy. Kathy’s child sees all this activity, witnesses Kathy’s preparation for meetings, sees her coming home disappointed, discouraged, losing hope. He hears the calls from separate providers to offer advice, to encourage her to pursue her rights. He takes a few calls from advocates. He knows his mother trusts these people, but they don’t help him or his mother. He worries about what will happen to him.*

### **Family-Centered.**

With family-centered practice families know and want more. They ask. They demand services. They engage their strengths. The Kansas Beach Center describes practice at this level as discrete from traditional medical models where the role of the health care professional is to look at the situation and tell the family what to do for the child. Key components of family centered practice include:

- focusing on whole families as the unit of attention;
- organizing assistance in accord with the family's strengths;
- normalizing and recognizing the typicalness of situations rather than emphasizing deficits;
- structuring service delivery to ensure accessibility, minimal disruption of family integrity and routine. (Family and Disability Newsletter, 1997).

Families select from existing service systems once they have information about specific services and what outcomes they can expect from those services. Their providers listen and attend to needs as the family identifies them. Providers offer information, services and the benefit of their professional training and experience, but it is the family who drives the plan and makes decisions about what is and is not working. Providers may become very frustrated in this role, as it threatens their professional training. Many feel pressed to meet the expectations of current political correctness and they may even justify weak programming as “what the family wanted.” The one-down relationship between provider and family denigrates years of professional training and experience with many youth. With family-driven, family determined supports, the family is at the center of determining their own needs.

In addition to their service providers, the family caregivers may also access their own independent network for information and consultation. State and national family organizations serve to connect the family with other families with similar needs and offer them information and support through training in advocacy skills and in representing their needs to state and national decision makers.

At the service planning process, selected families may be loosely connected to other families but will be outnumbered by the provider community in number and background information. Providers, particularly at the state agency level, frequently recognize the state family organization and use it to recruit family participation in, among other things, planning and in legislative advocacy.

At planning levels, words like family-driven permeate service discussions. Power and control issues dominate. The family organization, which began with a mission of advocacy and family support, becomes a provider whose mission is to meet the unmet needs families identify. Though desired, in practice this level is generally available only to mainstream middle class culture. Families of different racial, cultural, and socio-economic status than their providers rarely experience this level of family-determined supports.

Family members frequently become frustrated because the attitude “make it as we need it” just really isn't very possible in most communities. Most agencies just don't have services or staff to meet flexible or changing needs.

*Connie shows up crying at the office of the state advocacy organization. Her son, Dante will be released at 3:00 p.m. today from the local private psychiatric hospital. He has been there three weeks. Connie states she has a wraparound team. They supported this placement. She says the team is wonderful. They support whatever she wants to do. Sobbing, though, Connie states now that she doesn't know what to do. She says her husband is at work, has told her whatever she decides is all right with him. She says she is afraid to take her child home. "He may kill himself and I won't be able to stop him." Dante sees the loss of her control. He sees that she is overwhelmed. He fears for his safety. He sees his parents wanting to make their own decisions, provide their own rescuers, sees them without the resources or strategies to control the situation. He loses faith in her capacity to manage and begins to rely on professional interventions, begins to see his own need to be rescued. He sees only crisis help, which is too little, too late.*

### **Team-Centered.**

At the right end of the continuum, family members say what they need and services are developed to respond to very specific needs. The family may ask to be its own case manager, with team members offering them the support they will need to effectively function in this capacity. The team calculates who and how this will be done. If needed, the team configures respite and attendant care to meet outcomes and works with the family's schedule as well as those of the provider community. Services are provided as requested.

Providers coalesce to offer supports and configure the team to support the family and each other. The team determines who should be at specific meetings. Team members hold many small meetings with only the people who need to attend due to the specific nature of the issues at hand. For example, school issues and/or crisis planning may include only select members who can offer support and services and who report to the team as a whole. The family selects team members and providers who already are informed about their needs. These team members identify others with the family's help. Formal categorical services and their providers (the therapist, case manager, attendant, and respite provider) may be directed by the team to identify treatment goals, deliver services to the child and shore up family and natural provider skills. Examples include training for neighbors or church members to de-escalate crisis situations or provide tutoring.

The parents use their own strengths and the strengths of the team to identify needs and find new and informal resources, even calling upon members of the team for input. The emphasis here is on the interdependence of services and the people who provide the services. People join the team and belong to the team because they offer help and support. This is the expectation and the practice. Everyone identifies and shares resources. The family's strengths are imbedded in the teams. Team members' needs are considered as well as those of the family and the members are flexible enough to respond quickly. For example, the child's teacher says, "I am unable this week (or this month) to provide this level of monitoring." Someone, anyone on the team, including the family members, says "What do you need?" And the teacher knows they mean it! Team members listen and configure supports to the teacher. Supportive responses are quick, expected, and delivered. Interdependence of the members is maintained. Diversity is honored. Members are invited to join the child and the



family team because they bring to the situation diverse resources, personalities, and cultures and supports (both informal and formal). Feedback loops are immediate. When services and supports aren't working, they are changed. Team members set joint service goals and track outcomes. They hold each other's services accountable and share the responsibility to shore up informal resources with their formal infrastructures. Each provider uses his or her expertise and training to offer direction to the team from one perspective and knows there are others. The dialogue is shared with the family.

At this level, family members are encouraged and supported to belong to their state organization and to attend state and national meetings. They begin to organize, to develop their own information infrastructure, to receive information, and to access information before and after meetings. Professionals and families receive mutual support for good work. Families provide needed advocacy to move the system forward, to improve policy, and to secure new money for services. At this level, there are implicit and explicit understandings that families need providers for their services and value their expertise. Providers value families because they are the experts on if and how well services work. They can best predict their success. Providers and customer families acknowledge each other's roles and articulate them clearly from time to time. Providers need the families to give their services to and recognize that the work they perform is only necessary because families need help and can offer help to others. Problems such as when to hold meetings become more complicated. Agenda are made and appropriate team members are selected. Time and place decisions are made to accommodate everyone on the team.

Children see the adults in their lives connected and responsive to meeting their own needs as well as those of the children. They see the parents in charge, see them having their needs met with the supports they learn to use and not use. The child sees his or her parents participating with autonomy and information to impact family and community decisions. The structure possesses some vital ingredients: democracy, voice, access, and ownership.

This point on the continuum of family-professional relationships suggests a respect and consideration for all members of the service delivery as well as service design teams. At this level, families are supported and decisions are made and shared.

*Recently in Emporia, Kansas, a single mother realized she had a crisis in managing her daughter's needs. She called the mental health center, asked for team direction. Team members available met by phone with her to address the immediate needs and arranged time for a "sit down" meeting. One member elected to do so, arriving at her house within 15 minutes to offer support. Kathy, the mom, made her decision because she had the support and direction of the whole set of resources that surround her.*

Compare this to the response of another mother, from Abilene, Kansas. Desperate when she shows up at the Keys for Networking office yesterday at noon, as her child is being released from the state hospital in three hours. Yes, she has a team. She called her case manager. The case manager told her whatever she decided, to let them know. They support her decision. She is crying because she is overwhelmed by her decisions and can't make any more.

The levels are important to examine because of the impact each type of relationship has on both family members and children as well as on the members of teams who provide services. The different types of parent, professional relationships shown in this document as levels, allow the members (families and professionals) involved in system change relationships to reach to “do it better” as well as to define where they are. It is difficult to involve in a meaningful way the people who receive services as well as those who offer them. It forces us all to take a hard look at how we do our work and examine what we achieve.

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## CHAPTER 6: PATHWAYS INTO THE FUTURE

For over a decade, we have been trying to effectively involve families in policy design, planning, implementation, and evaluation of services and supports. We still do not have an easily replicable “model of family involvement.” A model that engages the diverse families who are the “customers” of the services and supports. We have not yet completely and consistently learned to employ family voices in decision making and problem solving. A variety of trainings have been successful in teaching skills of engagement at the policy level, or in helping unveil the fears behind anyone’s hesitation to fully involve families. However, nothing has changed the behavior of the players enough to create sustainable and effective engagement—an engagement that fully recognizes the interdependence inherent between the members of the system, that optimizes every member’s role, and that provides consistent feedback loops. As we stated earlier, the rhetoric far surpasses the practice.

As discussed in Chapter One, we believe that the core of the problem is the very language being used in discourse about this goal called family involvement. The term itself implies that families are outsiders to be brought in and involved by the insiders. It fails to recognize that families are already integral members of the ecosystem that raises and serves children. We looked at the perceived risks of engaging with other members of the system (Chapter Two) and the inherent struggle over power (Chapter Four.)

When one cannot find the answer to the puzzle, it is sometimes helpful to move around the card table and view the pieces from other vantage points. That process of shifting vantage points, we believe, is the first step toward discovering new strategies. We must change our perspective of the problem. To that end, we reframed [Chapter One] the problem to: **that which must be overcome is the failure to develop and maintain authentic customer family voices which provide the necessary feedback loops (the dynamic exchange of resources, such as information, services, expertise, money, etc.) for the creation and ongoing evolution of the system.**

So, with the issue reframed, we offer a few points as we begin our journey into the next evolution of improving systems that serve and support children:

- **Families** of the children intended to be served and supported are core members of any system. For the sake of designing and implementing effective, sustainable services and supports for children, **authentic customer/family voices** must be depended upon for the rich resources they bring (information, intimate knowledge, monitoring ability, etc. (See Chapter Four.)
- The **interdependence** of all members of a system — and the interdependence of the system and its community — should be the basic premise upon which all else is built.
- **Optimization** of every role within the system is basic to the overall quality of the system. Optimization of the role of family voices is best supported through **organized networks of families.**

- The interdependent relationships between members of the system should be built upon clear, consistent and mutually agreed upon commitments to one another. These may best be constructed through **outcome based contracts** — for example, between provider organizations and family network organizations.
- Successful evolution and sustaining of systems can only be accomplished by persons with congruent **personal values**.

Successful strategies **to develop and maintain authentic customer family voices which provide the necessary feedback loops for the creation and ongoing evolution of the system should target two specific areas: the processes that drive the system and the personal skills of the people participating in the system.** Replicating concrete models of family involvement is not enough, nor will it overcome the barriers, which exist in communities which have been about the work for a long time. It is time for methods that cultivate more productive and effective interactions between members of the system; methods which enrich the processes that drive the system and cultivate an ever-improved system.

The strategies we offer include process improvements, personal skills identification, and the development of learning communities as a possible method for improving both process and personal skills.

### **Strategies to Improve Process.**

- ⇒ Family Network Organizations — Consistent local, regional, state and national support of family network organizations would aid in optimizing the roles families play in the design, implementation, and evaluation of systems that serve and support children with mental health problems. Support in the form of fiscal resources, training, information sharing, and recognition will form one direction of the feedback loop. Through this loop, other members of the system are cognizant of the expertise, information and commitment of families.
- ⇒ Family Network Organizations, run by families, provide the infrastructure to at least:
  - identify system members who want to participate in particular levels of the system;
  - train them in the process of participation;
  - provide them with a continuous flow of adequate information;
  - ensure the inclusion of diverse families in messages that get carried; and
  - provide logistical support for the roles of families in the system.
- ⇒ Feedback Loops — Recognition of the resources each system member brings to

the process and conscious implementation of pathways for the continual exchange of those resources is integral to moving forward. The most simple example is the exchange of a service from the provider for feedback from the family about whether or not it worked. The family's feedback serves to enhance the providers service and so on.

- ⇒ Outcomes Based Contractual Agreements — The exchange of resources can be enhanced and supported by the development of mutually agreed upon identification of the resources to be exchanged along with the terms of that exchange. For example, contracts between provider organizations and family network organizations should spell out mutually negotiated outcomes, terms of satisfaction, available corrective strategies, and timeliness

### **Identification of Critical Personal Skills**

The personal skills essential to being effective members of an evolving system are the same for every level of the system - upper level administration, mid level management and front line workers. These skills go far beyond the technical and theoretical methods learned in school. They are, we believe, the basic methods necessary to fully participating as an interdependent member of the system. They include the ability to:

- lead with authority — authority gained through employment, appointment or election;
- lead without authority — authority gained through the ability to influence others;
- have broad and critical perspective;
- nurture self and avoid burnout;
- persevere and be resilient;
- maintain ethical congruence between work and life;
- cope with ambiguity;
- engage diversity and complexity in problem solving and decision making;
- constructively engage with “otherness.”

The next question is how does the system support changing processes and improving personal skills. Systems and system members who accept the challenge of making these changes will be the pathfinders for the next

evolution of systems. One method currently in vogue in the organizational growth arena is the use of Learning Communities.

### **Learning Communities as a Strategy.**

To adapt our work in a way that incorporates a different way of thinking about the relationships between families and professionals. This restructured work recognizes the power dynamics and nurtures a sense of interdependence, requires new ways of operating that take us beyond merely understanding the theory and issues to a different way of behaving. Developing learning organizations or learning communities is one strategy that has been suggested and tried in diverse settings where similar issues are involved.

*“Learning communities can help people to become more aware of when they are unintentionally doing damage as well as recognize and validate positive actions they have taken. They can help people assess their own actions, words and attitudes as well as the implications of group norms and behaviors.” (Chang, 1997).*

Learning communities are settings where people can openly and frankly discuss issues in order to deepen their individual and collective understanding. They create time and opportunities for people who will be working together on a sustained basis over a period of time to learn about each other. They are places where people can disagree and challenge each other’s opinions while agreeing at the same time to be open to listening to the words or actions of another without passing immediate judgment. They provide an opportunity for participants to express and process their emotions related to the issues at hand. Emotions are understood and valued as a part of the process. They create opportunities to understand why different perceptions exist so that differences can be accommodated in the movement forward.

A Learning Community can be a new group or an existing committee, board and staff of an initiative or organization that is willing to explore issues of the relationship between family members and professional staff. The community must be willing to take time to reflect on their own dynamics, practices, and how issues are playing out in their interactions. “This requires setting aside time to build personal relationships, pay attention to group process, and address underlying power dynamics in order to establish trust and ensure no voice is marginalized or silenced.” (Chang, 1997).

Three resources that describe the principles and practice of learning communities in different contexts include: (Senge, Kleiner, Roberts, Ross, Smith, 1994).

- Senge, Kleiner, Roberts, Ross & Smith (1994) in *The Fifth Discipline*, and the accompanying *The Fifth Discipline Fieldbook*, describes the construct of a learning organization. The authors suggest the necessary tools for building the disciplines of systems thinking, developing new mental models, shared vision, and team learning. These are the foundations for a learning organization or community.

- Chang, of California Tomorrow, in a recent publication, *Community Building and Diversity. Principles for Action*, recommends developing learning communities to promote deeper individual and collective understanding and support sustained action around issues of equity and diversity.
- Barr, of the Cornell Empowerment Project, proposes learning groups (which he calls study circles) as a vehicle for experiential learning for human service workers to better understand dominant and alternative views of power. Study circles provide a forum where participants can come to discern the use and abuse of power in their institutions and communities. This gives them the opportunity to transform their own helping paradigms from power over to “power with.” It can also facilitate a similar transformation in their communities. Barr has developed a guided curriculum that calls for participants to meet in a small group for 1-1/2 hours per week for 13 weeks. It involves critical reflection, and developing action strategies. The study circles provide a supportive and challenging learning environment where people can share ideas and enhance each other’s learning.

Senge quotes a participant in a community building effort based on building a learning community as saying: “It’s about telling the truth and encouraging others to do the same.” This is such a simple statement, but may be the very essence of the change we are seeking. How can we create environments that support the capacity of our partners to do this as a means of gaining understanding and seeking effective ways of making the most of our mutual needs, concerns, and promise?

The “strategies” we offer are challenges that beg the reader to be first, excruciatingly honest about personal values and second, to be creative and to take risks. We believe, as stated earlier, that if this paper were written a year from now it would be very different. But for now, the focus needs to be on increasing the ability of the systems to learn from their own experiences and develop personal leadership skills amongst the members of the systems.

## REFERENCES

Chang, H. (1997). *Community Building and Diversity: Principles for Action*. San Francisco: California Tomorrow. p. 31.

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## IN CONCLUSIONS: A PARENT'S POINT OF VIEW

Valerie Burrell-Mohammad

*In conclusion human tragedy has set the tone for some of the thinking, and, sad to say, yes facts for this document regarding family-professional involvement. It is clear to me that no matter what the color of skin, educational background, or the community from whence we came. There is a mindset across all levels of thinking and areas of expertise that continues to exclude parents' experience and/or knowledge base as an asset to the process. Knowledge, however we offer it, that's rarely valued or shared! But I'm convinced in spite of what seems to be at times never-ending obstacles, parent-involvement across all systems is here to stay. And the people involved (at least those of us working on this document) do care, are committed, value and respect one another, experiences and all! I can still see the light — a light that shines brightly. A new world order for all children and every family!*